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THE DISABILITY SERVICE SYSTEM

A Report on Existing Services, Barriers, Gaps and Duplications

December 2001

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INTRODUCTION

This report is an updated, revised edition of one that was originally distributed in April 1998. Its purpose is to provide information regarding the service system for people with disabilities in the Commonwealth. The information reflects the disability service system as of December 2001. It does not reflect cuts mandated by the Legislature's late passage of the Fiscal Year 2002 budget. The report includes recommendations to the Governor and the Legislature on ways to improve the accessibility and delivery of services. This is a project of the Inter-Agency Disability Services Coordinating Council (Executive Order 352).

The report is divided into five sections. The first includes **Findings and Recommendations** that generally apply across the system. Subsequent sections include **Findings and Recommendations** that are specific to age groups. Section two looks at disability services for **infants and toddlers from birth to age 3.** It is followed by services for **children from 3 to age 6, older children, adolescents and young adults from 6 to 22 years of age,** and concludes with the fifth section, which focuses on **adults ages 22 – 59.**

Appendixes A, B, and C are a series of tables, which apply to each of the sections. (Appendix A combines infants and children through age 5.) They identify programs/services from a cross-agency perspective. The tables contain basic information on the various agencies that provide services, the methods by which services are accessed, eligibility criteria, funding sources, barriers and comments. Accompanying footnotes elaborate particular aspects of a chart's text where appropriate.

The Council's goal is to better serve recipients of state disability services by increased coordination of services, information, and communication. Its members consist of representatives from the following agencies and departments that deliver services to people with disabilities in the Commonwealth: the Massachusetts Office on Disability (MOD) whose director chairs the Council; Massachusetts Rehabilitation Commission

(MRC); the Massachusetts Commission for the Blind (MCB); the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH); the Department of Mental Health (DMH); the Department of Mental Retardation (DMR); the Department of Transitional Assistance (DTA); the Massachusetts Commission Against Discrimination (MCAD); the Disabled Persons Protection Commission (DPPC); the Governor's Commission on Mental Retardation; the Architectural Access Board; the Massachusetts Developmental Disabilities Council; the Department of Special Education; the Division of Medical Assistance (DMA); the Department of Public Health (DPH) and the Executive Office of Transportation and Construction (EOTC).

ACKNOWLEDGMENTS

Information for the report was obtained from members of the Council, and numerous other sources. On behalf of the Inter-Agency Disability Services Coordinating Council, thank you to everyone who contributed.

METHODOLOGY

The Inter-Agency Disability Services Coordinating Council sought information for the original report from a variety of resources. It began with:

Questionnaires:

A questionnaire was sent to all Inter-agency Disability Services Coordinating Council representatives. It requested information on: agency function, target population, services provided (programs and their descriptions), method of accessing services (direct self-referral or indirect), eligibility criteria, providers of services (public or private), funding sources (state, federal, private, or other), service gaps, numbers on waiting lists and average time waited, unmet need for services including an explanation of the way that need is computed, percentage of dollars allocated to service delivery, and administrative costs vis-à-vis direct service costs. A similar questionnaire was also sent to a group of community non-profit agencies that represented and worked with people with disabilities.

Interviews:

Follow-up phone calls and interviews were made to program heads in both state agencies and community-based non-profits. In addition, numerous phone and in-person interviews were conducted with consumers, family members, and advocates in both the state system and the community. These interviews addressed the individual's personal experience in seeking services through the public system including its community-based contractors. Interviews focused on issues that were perceived as barriers to, or gaps in service, and recommendations for reforms which would facilitate improvements in service delivery.

Supplementary Readings:

Further documentation was provided through reports that focused on specific issues and services, agency websites and documents that explicated eligibility guidelines and regulations.

Reports:

The information gathered originally was compiled into three reports and distributed for comments before being produced. The first report was issued in December 1995, the second in May 1996, and the third in June 1997.

This report is a compilation of those that preceded it. It has been updated by the appropriate agencies to reflect the current status of the various programs identified within.

Disclosure:

It should be noted that not all agencies represented on the Council agreed with all the Findings and Recommendations included in this report. However, the editors believe the information is objective and hope that it will be helpful in coordinating a more effective delivery system.

GENERAL FINDINGS

1. The disability service system, in general, is **fragmented;** it requires transitions - frequently for children who are continually aging out of systems - and is disruptive to families and consumers. In all cases, fragmentation is due to the fact that the **system is driven by separate funding streams, different eligibility criteria, and agency focus rather than individual need.**

2. **Case management services** are limited. They only exist for small populations: some individuals who are deaf, have mental retardation, mental illness or a head injury. Those who receive these services are usually among the most severely disabled. **Nothing exists** for other categories of disability and for a vast middle group (disabled, but not severely) who flounder trying to access and piece together services on their own. This lack is particularly problematic for people who are newly disabled.

3. **Eligibility criteria preclude** some consumers from receiving appropriate services either because of **gaps between services** for which an individual is eligible (this is apparent in criteria based on age and/or IQ), or because some consumers with **less common disability diagnoses** or with complex service needs do not meet specific criteria. For example, children and adults with developmental disabilities, including **autism spectrum** (e.g. Autistic Disorder, Pervasive Developmental Disorder (PDD), Asperger's Syndrome, Rett's

Syndrome and Childhood Disintegrative Disorder)[1] receive a patchwork of services from various agencies because their disability usually does not meet the specific criteria of a particular agency.

Family income is also a major factor in eligibility for services. MassHealth, a primary funding source for medical treatment and support services for people with disabilities, is available to those who are income eligible – for children in families with income at or below 200% of the Federal Poverty Level (FPL) and for adults with income at or below 133% FPL.

4. No accurate numbers exist on the **"unmet"** need for services. Waiting lists only identify those people who are in the system, and often on waiting lists for more than one agency, and current projections of the unmet needs are extrapolations based on national disability prevalence rates.

5. **Transportation services** are essential to people with disabilities who live in the community or in facilities such as nursing homes. These services are defined by their funding source, or they may be tied to programs with which agencies have contracts. This results in a system that is **piecemeal, uncoordinated, and in some cases, duplicated.** Individuals with disabilities also rely heavily on **public transportation**. Some metropolitan areas in the Commonwealth have vast public transportation systems that frequently do not meet the accessibility standards mandated in the Americans with Disabilities Act (ADA) and other laws. In contrast, rural transportation services are both inadequate and extremely limited, if they exist at all. In addition, the **Regional Transit Authorities (RTAs)** must contend with an expanding customer base – the result of an aging population, federal laws, and lack of full accessibility in public transportation systems – and a lack of new dollars to meet this growth. Also, many communities pay into RTA districts, but receive no services.

6. **Housing resources** for individuals with disabilities and/or their families, including home adaptations such as wheelchair ramps or an accessible bathroom, are **limited.**

7. The same services within the same agency may vary **from region to region**.

8. **Information and Referral (I&R)** systems, as the linchpin of disability services, are fragmented and limited, thus creating barriers to services for consumers whose needs go beyond the immediate agency through which they entered the system. Most existing systems are **not multilingual** and as such impede access for individuals for whom English is not the primary language.

9. **Protective services and abuse investigations** exist within five state agencies (e.g. DPPC, DMR, DPH, MRC, and DMH), all, but one of which (DPPC is an

1 "Exploring the Options for Young Children with Autism", Massachusetts Department of Education, Fall 1998.

investigation agency) provide services for people with disabilities. In some cases services are duplicated, lack uniformity, and are too narrowly restricted by the statutory definition of abuse.

It should be noted that in cases involving individuals with mental retardation significant progress has been made as a result of a new Memorandum of Understanding (MOU) with the District Attorneys. The MOU ensures that the most serious allegations (felonies) will be investigated by law enforcement professionals.

10. **Crisis intervention** and **emergencies** are intensive and costly. Programs (such as respite) and funds for pre-empting a crisis and/or managing occurrences are extremely limited.

11. The system for obtaining **Criminal Offender Record Information** (referred to as **CORI** checks) is **expensive** for individuals who use personal care attendants (PCAs), and **limited** in terms of the information it provides. For example, if an individual uses 5 PCAs/week, s/he is faced with a $10 application fee for each name submitted, and the information regarding each PCA is limited to arraignments in Massachusetts. CORI checks of an individual are based solely on name and date of birth, rather than **fingerprints which would verify identity.**

12. **Early and Periodic Screening, Diagnostic, and Treatment (EPSDT**) is a federal mandate to state Medicaid programs that they must deliver all medically necessary services to all Medicaid-enrolled children under 21 years of age. Under the requirements of EPSDT each Medicaid program must establish a schedule of preventive health care services that relate to health, nutritional and developmental services. The screening program defines services to which all children who are enrolled in Medicaid are entitled. School health personnel, under contracts with the Division of Medical Assistance (the **Municipal Medicaid Program**), work to enroll eligible children and adolescents in MassHealth through which they receive primary and preventive health care services in accordance with EPSDT requirements.[2] However, **significant gaps** exist for **children in mental health services**.

13. **Employment statistics** for working age (i.e. 18 – 64) individuals with disabilities are dismal. **Almost 70% are unemployed**.[3]

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[2] Information on EPSDT found on DMA's website under: MassHealth Title XXI State Plan Prepared by The Division of Medical Assistance, Executive Office of Health and Human Services, The Commonwealth of Massachusetts, Section 2. General Background and Description of State Approach to Child Health Coverage (Section 2102 (a) (1)-(3) and (Section 2105) (c)(7)(A)-(B), 22.1 **The Municipal Medicaid Program.**

[3] National Organization on Disability, "Employment Rates of People with Disabilities", excerpted from, N. O. D./Harris 2000 Survey of Americans with Disabilities, July 2001.

14. While MassHealth offers insurance coverage to working and non-working disabled adults through its Commonhealth program, most major federal programs, such as **SSI/SSDI**, create **disincentives to employment for people with disabilities** (through the substantial gainful activity rule) by focusing on one's general inability to work as proof of total disability.

15. There are not enough **interpreters for the deaf** in the Commonwealth, particularly those who are certified to interpret at legal hearings such as those at the MA Commission Against Discrimination (MCAD), or in the court system as well as in health and human services agencies.

16. The **Massachusetts Commission Against Discrimination (MCAD)** has no regulations pertaining to cases of discrimination against people with disabilities in places of public accommodations. The state law, as it currently stands, prohibits discrimination, but there is no provision for reasonable accommodations.

17. Individuals who seek to **file discrimination complaints** with MCAD are often confused about the types of issues MCAD adjudicates as well as the process for filing a case and the kind of documentation needed to prove discrimination.

GENERAL RECOMMENDATIONS

1. To minimize systemic fragmentation and frequent transitions:

    - Remove rigid category definitions
    - Utilize inter-agency service agreements
    - Implement appropriate legislative and regulatory changes
    - Seek federal waivers to restrictions based on funding source
    - Increase outreach and education to consumers at "transitions" and when systems and procedures change to avoid confusion and frustration, interruption and termination of services

2. More case management services need to be available in the disability service system. To preclude duplication of case management services when dual or multi agency services are required, delegate responsibility for an individual client to a **lead case manager and define agency links**. In some cases, a co-case manager may be appropriate to provide assistance to the lead regarding technical assistance in a specialty area. In most other cases, when more than one agency is involved, the services of each should be defined in a service plan and should be complementary.

3. Develop a strategy around **"gap" consumers** who are not receiving vital services due to eligibility criteria. Consider **developing and funding a distinct division** for individuals with **developmental disabilities** within an existing agency. That **division** will have responsibility for oversight and care coordination for those populations that now piece together or go without services all together.

The **Statewide Head Injury Program (SHIP**) which is housed in MRC represents an example of such an entity.

4. Develop a strategy to fund outreach efforts that aim to inform **individuals who need services but are not in the system**, about available services and how to access them.

5. To improve efficiencies, cost effectiveness, and user friendliness in the public **transportation system**:

   - **eliminate eligibility criteria** for receiving public transportation services between the systems which serve the elderly and individuals with disabilities,
   - **coordinate funding streams, transportation routes, and schedules,**
   - increase **outreach and training** in accessing and using existing rural transportation services,
   - establish a **task force** to study the **cost effectiveness and impact on consumers**, of eliminating the brokerage system currently utilized by the Regional Transit Authorities (RTAs), and to **identify potential revenue sources** for expanding both the currently limited fixed route service and transportation in rural communities,
   - increase funding of the **MBTA RIDE** and other **regional para transit** services to increase availability.

6. Implement legislation passed as part of the 2000 Transportation Bond Bill which will allow communities that pay assessments to the MBTA, but do not receive RIDE services, to develop a transportation system for the disability community. Include a 50% offset against those communities' MBTA assessment.

7. Expand affordable, accessible **housing** options for people with disabilities by:

   - Increasing funding for the **Home Modifications for Individuals with Disabilities Loan Program (HMDL)** that is administered by the Massachusetts Rehabilitation Commission,
   - Working with federal funding agencies to provide **adequate subsidies** for housing on the open market,
   - Encouraging the **development of community programs,** such as those currently provided by civic and religious organizations, which donate labor and materials for home modifications,
   - **Increasing access to homeownership by expanding existing tax** incentives that provide low interest loans and low down payment requirements to eligible consumers,
   - Ensuring that **adaptive and universal design** as required by law is implemented into all public housing stock,
   - Introducing the concept of **"visitability**" in all new construction so that people with disabilities have the basic access they need to go to a neighbor's house.

8. **Expand the existing disability Information and Referral Program in the Massachusetts Office on Disability (MOD)** to provide a broad range of information through a single source, which is available to all people with disabilities, agencies, and individuals outside the system. This program is already accessible statewide through an 800 number and by TDD (telecommunication device for the deaf). It also provides cross-disability information.

9. **Consolidate abuse investigations** into a single, independent agency and expand its jurisdiction to **include:**

    - neglect and abuse by individuals other than caretakers,
    - financial exploitation,
    - people with disabilities of all ages.

10. Provide **adequate resources** to cover the expanded legal and practical capacity including forensic experts.

11. Create a **flexible funding pool** to be used by service providing agencies in crisis **prevention and emergencies.**

12. Investigate tying into **a national, centralized database** that provides criminal offense records for individuals who provide PCA services. Consider requesting funds for this program from the **Health Care Financing Administration (HCFA).**

13. Continue to promote outreach to **identify** and **enroll** eligible children and adolescents in MassHealth to ensure that the EPSDT guidelines ensure good, preventive health care for all children.

14. Continue to work for improvements for people with disabilities who receive SSI/SSDI through the Ticket to Work Legislation and other programs. Explore additional improvements in the Medicaid Buy-In programs – i.e. Commonhealth through the Medicaid infrastructure grant.

15. **Increase collaboration** between the Department of Education and human service agencies**, and assign responsibility for assuring coordination** between DOE and human services agencies.

16. Establish **criteria for children's services** and apply it through age 22.

17. **Increase availability of training and curriculum** in community and state colleges on the subjects of American Sign Language proficiency and also in other modes of communication access.

18. Recruit and offer tuition reimbursement to students who are interested in studying and becoming certified **in American Sign Language, interpreting, and computer assisted real time (CART) transcription.**

19. **Promulgate MCAD's** recently written **Public Accommodations Regulations**. If this is done, perhaps the agency can contract with the Department of Justice to investigate Title III ADA public accommodations cases. (MCAD currently contracts with the Equal Employment Opportunity Commission (EEOC) to investigate ADA employment cases, and with the U. S. Department of Housing and Urban Development (HUD) agency to investigate housing cases filed under the Federal Fair Housing Act.)

THE SERVICE SYSTEM FOR INFANTS AND TODDLERS FROM BIRTH TO AGE 3

Early Intervention (EI) is the primary program that provides services for children (from birth through age 2) with disabilities, or children who are at risk, biologically or environmentally, of developmental delay. EI is housed in the Department of Public Health's Children with Special Health Needs Division and funded, in part, by Medicaid (DMA). The program focuses on including and empowering families - i.e. the service environment adapts to the family, it is supportive of caregivers, and it trains parents to provide needed skills. **Services after age 2 are not provided through a single program.**

FINDINGS:

1. The voluntary aspect of the EI program is essential to the program's goal of empowering families and Massachusetts has one of the highest enrollments in the country testifying to the program's success. However, there may be some children whose development may be at **environmental risk** [4] of delay due to the fact that their parents haven't enrolled them in the program. This may occur if the parents are unaware of a potential delay in their child's development.

2. Exact numbers of families of children with disabilities or at risk of developmental delay are unknown and **outreach** is limited by budgets and funding caps.

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[4] "...Environmental risk infants are those who are biologically sound but whose early life experience, including maternal and family care, health care, nutrition, opportunities for expression of adaptive behaviors, and patterns of physical and social stimulation are sufficiently limiting to the extent that they impart high probability for delayed development " (Early Intervention Operational Standards, 5/94).

3. Services specific to certain severe disabilities or those included in the **low incidence** [5] **spectrum** such as autism or related disorders, deafness, hard of hearing and blindness, are in place with ready access and complete training, to interface with specialty providers. However, providers of **special services** are limited in some areas of the state and some children may be **underserved** for this reason.

4. Early Intervention programs serve children in natural settings such as integrated toddler groups in day care. However, integrated groups should not preclude the need for **day care workers** to be trained in working with children who have **specific disabilities**, nor should day care be considered a substitute for training parents in how to care for a child's disability.

5. DMR has dollars for respite care for eligible children as do some regional EI service providers, but generally there are **no DPH dollars** for providing this service in the EI program. (Note: legislation was recently passed providing $1 million for respite for children in the EI system who have special medical needs.)

6. A **shortage of in-home nursing staff** exists for families of children with special health care needs. [6] This has become a critical issue that severely impacts a family's ability to care for its child at home.

7. **Housing resources** for families, including home adaptations such as wheelchair ramps or an accessible bathroom, are limited [7].

8. A smooth **transition process** is needed for families moving from **EI,** which is family focused, to **Special Education** which is child focused.

9. Although funding for EI services is an entitlement for the state, **adequate funding** for individual services for children with disabilities or at risk of developmental delay is not necessarily assured.

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[5] Low incidence disabilities are severe disabilities that have a low prevalence rate in the general population. Each low incidence disability has unique needs and requires special knowledge of professionals and parents in order to effect maximum development.

[6] "There's No Place Like Home, Meeting the Housing Needs of Families of Children with Special Health Care Needs", A Report for Franciscan Children's Hospital and Rehabilitation Center, Boston, Massachusetts, December 1994, p. 3.

[7] There's No Place Like Home, Meeting the Housing Needs of Families of Children with Special Health Care Needs, pp. 20-25.

RECOMMENDATIONS: (Some recommendations reflect more than one Finding)

1. Expand **outreach and education** to professionals who are involved in the identification, diagnosis and treatment of children with disabilities.

2. Increase **training in parenting programs** to prepare parents in responsible child-rearing skills. These programs are inherently preventive in that they help mitigate burnout, abuse and neglect among parents of a child with a disability or at risk of developmental delay, who are unprepared for the task of raising a child.

3. Considerable expertise on specific disabilities exists in the present disability agency structure which can be more effectively utilized through **inter-agency collaboration** to:

    - Continue and expand ongoing efforts between the Department of Public Health and the Department of Education to facilitate the **transition** process for families moving from EI to Special Education
    - Expand the provision of **special services** for certain severe or low incidence disabilities in underserved areas

4. **Expand funding for respite** services; they are **cost effective,** and may preclude the need for **expensive, intensive,** family support services or institutionalization when a **crisis** occurs.

5. Work with home health and other nursing agencies and/or residential services to **promote in-home nursing services.** Providing services, such as shuttle buses or escorts, may encourage health care workers to provide nursing services in areas considered hazardous and/or rural.

6. The **potential for expanding childcare services** in the under 3 population should be increased. EI should not be the only source.

THE SERVICE SYSTEM FOR CHILDREN FROM AGE 3 TO AGE 6

FINDINGS:

1. Children who age out of EI when they become 3 years old, who do not have a **diagnosed disability** that meets the **Special Education eligibility criteria** [8] (most likely the at-risk child, such as one who is HIV positive and children with invisible problems such as emotional disabilities), may experience some **service**

[8] " Is Special Education the Right Service?, A Technical Assistance Document prepared by the Massachusetts Department of Education", Working Draft, March 2001.

gaps [9]. This is due to the fact that the broad eligibility requirements for EI differ from the eligibility criteria of Chapter 766.

2. In some cases, a child who does not meet Special Education eligibility, may be eligible for pre-school services through a School District funded program which is not part of special education, or s/he may qualify for a state subsidized child care program. Those children for whom neither of these options is available, **may sit home until they are old enough to enter the school system**.

3. **Early childhood programs** (pre-kindergarten) are available in 335 of 351 cities and towns, but **may not be available** to **all children** due to restricted eligibility criteria and/or limited funds.

4. **Preschool programs** that do exist are often **neither affordable nor handicapped accessible** to all 3 and 4 year olds.[10]

5. Providers of **special services** for low incidence disabilities are limited in some areas of the state.

6. **Access to specialized programs** may be impeded by a lack of transportation for children and their families.

7. **Mental illness in children under 3** is addressed through Early Intervention; however, most Early Intervention providers do not have the clinical expertise to adequately identify and address these problems. **Children from 3 - 6 years** old fall into a **gap** for the following reasons: (1) while special education serves those identified as in need of continuing service, **school systems** are reluctant to identify children with emotional and behavioral problems as having an emotional disability, and (2) the **public mental health system** is oriented towards treatment of severe emotional disturbance (SED). As a result, children who may have a mental illness but do not meet the special education disability definition may receive outpatient services but will **not be eligible for more intensive services**.

RECOMMENDATIONS: (Some recommendations reflect more than one Finding)

1. Implement a **funding plan** which ensures that all pre-school children have the opportunity to participate in **early education programs** in their communities.

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[9] A child's continued need for services does not assume that the issues, which made that child eligible for the EI program, have not been successfully addressed within the limits of that program.

[10] "Securing Our Future, Planning what we want for our youngest children" Future Trends-Volume VI: 2001, Executive Summary, p. iii.

2. Explore the impact and potential benefits that regional consultants in special services have in regular day care settings. Services and supports provided by an Early Intervention pilot project, the **Regional Consultation Program,** to children in integrated day care programs may have an additional benefit of increasing both the comfort level and knowledge of day care workers who continue to work with those children aging out of EI (but staying in day care) who may still be "at risk", such as the **child with mental health problems**, but who do not meet the eligibility for special education preschool programs.

3. Establish a **funding pool for transportation** to programs and services for low-income children with disabilities and their parents.

4. **Itinerant consultants** with expertise in specific disabilities should be utilized to provide joint training and assist with Individualized Family Support Plans (IFSPs) for Early Intervention, Preschool and HeadStart teachers in areas where special providers are limited.

5. A **nationally recognized assessment tool to determine mental illness** in very young children should be utilized so that children can receive necessary services.

6. Establish a funding pool for Assistive Technology and personnel who can communicate in sign language for educational settings covering K-12.

THE SERVICE SYSTEM FOR CHILDREN, ADOLESCENTS AND YOUNG ADULTS FROM AGE 6 TO AGE 22

Special Education is the focus of most services that are provided for children and adolescents with disabilities once they reach school age. These services may start for eligible children when they age out of the Early Intervention Program at the age of 3 and enter preschool. They end when a student either graduates from high school or reaches the age off 22, at which time they may enter the adult service system if eligible.

FINDINGS:

1. **Linkages** between **local school districts** and the **human service agencies** that have expertise in particular disabilities vary significantly across the state. Recent **changes in special education regulations** move the standard from maximum feasible benefits (MFB) to free and appropriate public education (FAPE). As Massachusetts implements the **lower federal standards**, the issue of weak linkages may be exacerbated as responsibility and costs for providing services shift from local school districts to human service agencies. Children may be **at risk of losing services as a result.**

2. Schools are writing **504 plans** for students with disabilities rather than **766 plans.** School systems have no guidelines or training in the differences between the two plans. Students may receive **inadequate or inappropriate services** as a result.

3. **Transition Planning**, an essential component of independent living in one's community after high school, **often lacks effective collaboration** with adult human service agencies, the primary providers of services for individuals entering the adult service system.

4. Adolescents who are aging out of the child service system are often faced with **gaps in services due to different eligibility standards** in the adult system. Additionally, a client may age out of one agency, and, due to eligibility criteria, be unable to meet the requirements for receiving services from another agency.

5. The present system of contracting for **residential programs** limits agencies and their clients (i.e. agencies must commit dollars prior to actual need and they are bound to the programs with which they contract). However, related to deaf children, it may be expedient to contract for this type of service in order to ensure the ready availability of staff in a residential facility who can fully communicate with children who use American Sign Language (ASL) or a manually coded English Sign System.

6. A **joint initiative** between the Departments of Mental Retardation (DMR) and Education (DOE) has been successful in **bringing home children** from residential schools and in preventing the initial placements. During the past 4 fiscal years, 40 children have been returned to their home communities from expensive residential schools, and 187 children have been prevented from going to such places by services which are provided in their **home communities** with their families.

7. Lack of **accessible transportation** is pervasive in the Commonwealth and creates major barriers for adolescents and young adults who are dependent on it to receive services and avoid social isolation [11].

8. There is a need for more **recreational and social** programs that include children and adolescents with disabilities.

9. The state licensing regulations do not specifically require **licensees of after-school programs** to be accessible.[12] (Note: regulations do exist requiring licensees of infant and pre-school programs to hold those programs in accessible places).

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[11] "RTA Transit Needs and Funding Analysis, Final Report", KKO & Associates, May 1996, pp.xix - xxi.

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act as well as the Massachusetts Public Accommodations law provide some coverage here.

10. The Department of Social Services' (DSS) important priority of protecting children from abuse has **inadvertently diverted attention** from serving the **needs of families in which a disability** exists.

RECOMMENDATIONS: (Some recommendations reflect more than one Finding)

1. Develop stronger linkages through **inter-agency service agreements (ISAs)** that support more effective coordination of programs and initiatives (such as School to Work), and **job-skills training** of consumers among DOE, MRC, DMR and other relevant agencies. This would be **cost effective** and result in **increasing job opportunities** for people with disabilities who experience high unemployment (nearly 70%[13]).

2. Create **written guidelines** for writing 504 plans and implement training for schools and parents that addresses the differences in **504 and 766 plans.**

3. Support **transition planning** as part of a student's special education program that effectively addresses a student's career needs and life experience. Assessments should be conducted early enough to establish a student's vocational aptitude and interests in order to preclude a break between school and employment training.

4. **Fund** services that are identified in **Chapter 688** and individualized transition plans when students age out of school or graduate.[14]

5. **Coordinate age-eligibility** standards among the various agencies delivering services to children and adolescents to facilitate transition planning.

6. Create a more **flexible system** for purchasing residential services that would enable agencies to **buy** program slots based on need and client-appropriateness; currently agencies contract for them.

7. Expand programs and increase intensive family supports so that residential care can be limited. It is more humane and sometimes far more **cost effective** to increase intensive family supports when a child with a disability lives at home than to provide residential treatment.

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[13] Statistic is derived from the N.O.D./Harris 2000 Survey of Americans with Disabilities. conducted by Louis Harris and Associates for the National Organization on Disability. See N.O.D. website (www..nod.org): Employment Rates of People with Disabilities.

[14] See "Chapter 688" Turning 22" Program, A Report to the Legislature", Executive office of Health & Human Services, William D. O'Leary, Secretary, October 30, 1997, Executive Summary, Conclusion and Recommendations, #1.

8. Use **itinerant consultants** to assist school districts in developing programs for challenging special education students. This may alleviate the need for out-of-district placements.

9. Establish a **mechanism for transferring funds** between **institutions and community-based services** so there are funds to support individuals who move from one part of the care continuum to another.

10. Require the state agency, the Office of Child Care Services (OCCS) that **licenses after-school programs**, to articulate the specific compliance requirements regarding **program accessibility** in their **regulations**.

11. Provide **training for DSS** workers in issues specific to children with disabilities and their families and collaborate, through Interagency Service Agreements (ISAs) with disability service agencies, on programs and services which would pre-empt crisis situations for families with a disabled child.

12. Develop a **support system for parents with disabilities** to enable them to keep their children rather than having them under DSS control and/or put up for adoption.

THE SERVICE SYSTEM FOR ADULTS FROM AGE 22

In most cases, after the age of 59, adults receive many services through the elderly system. Individuals with certain disabilities such as blindness, mental retardation and mental health may continue to receive some services specific to their disability through the disability agencies in collaboration with providers from the elderly system.

FINDINGS

1. In some cases, **managed care has created confusion for consumers.** It most often requires additional paperwork, prior authorization forms, and dependence on others to complete procedural tasks before services can be received. (Providers also must comply with excessively complicated administrative procedures.)

2. For **mental health consumers** acute care is covered by Medicaid and continuing care is covered by the Department of Mental Health. The full range of community-based services is not available to those covered at the acute end of the care continuum. Thus, a **discontinuity of services as well as limited services**, due to different funding sources, exists for those moving from acute to intermediate to long-term care as well as for those moving back into the community..

3. Standards for procuring **durable medical equipment (DME**) are clear, but some aspects of the **process for complying** with them are confusing to consumers and advocates. For example:

   - **individual vendors** who contract with the Division of Medical Assistance may tell a consumer that Medicaid will not pay for a certain piece of equipment when, in fact, it will
   - if Medicaid denies the equipment requested by an individual, and prescribed by a physician, the appeals process for proving **medical necessity** is complicated
   - if the durable medical equipment ordered for the consumer is found to be uncomfortable or inappropriate (I e. a wheelchair that is too large or not large enough for the individual), it is not clear how to remedy the problem. While there is an 800 member services line for questions, consumers and advocates report that representatives do not always have clear answers.
   - **MassHealth's vendor list is** active and difficult to keep up-to-date all the time. Advocates report hearing from consumers that when consumers call MassHealth's information line to find a Medicaid vendor in their area from which to purchase a piece of durable medical equipment, the reference given to them by MassHealth's I and R often no longer exists.

4. **Civil rights complaints** involving **employment issues** take too long to resolve. Complaints are filed with the MA Commission Against Discrimination (MCAD) whose regulations allow 18 months to make a determination of probable cause or not.

5. Clients often are not given a **complete menu of options** when working with their vocational rehabilitation counselor on developing an **Individual Plan of Employment (IPE).** For example, transportation services may be available to certain jobs, but unless the client asks about it, its availability may not be included in the services mentioned.

6. Segregated work environments (**sheltered workshops**) continue to be utilized for some consumers, thus **isolating** those employees from the benefits of integrated, interactive work experiences.

RECOMMENDATIONS (Some recommendations reflect more than one Finding.)

1. Increase **outreach and education** to consumers at "transitions" and when systems and procedures change to avoid confusion and frustration, interruption and termination of services.

2. **Extend the full range of community based services**, including acute, intermediate and long term care, to all consumers who are **Medicaid enrollees** regardless of which coverage they receive.

3. **Clarify the Medicaid appeals process** for consumers and provide that information in a timely way so that individuals are able to gather the facts they need to present a compelling case for their particular need. For example, include the specific reason why a piece of equipment was denied (i.e. a less expensive alternative might work) and provide information on brand name and vendor so that a consumer has the opportunity to try it out before an appeal's hearing.

4. Streamline the **adjudication process** for resolving **civil rights cases** by prioritizing those that can be quickly resolved. For example, reasonable accommodation in employment cases can often be worked out before tension develops and the employee's job is jeopardized.

5. **Ensure that clients** who are working with **vocational rehabilitation counselors** are informed about available services, such as transportation, that may provide essential supports to their vocational goals.

6. **Redirect funds** that support **sheltered workshops** to supported/competitive employment.

APPENDIX A

TABLE OF SERVICES FOR INFANTS AND CHILDREN FROM BIRTH TO AGE 6

CASE MANAGEMENT/SERVICE COORDINATION: BIRTH TO AGE 6				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Public Health (DPH): Early Intervention Program (Birth to age 3)				
• Direct and Indirect • Neo-natal Intensive Hospital Care Units (NICUs) • Generic Birth Hospitals • Primary Care Doctors • Self-referral (Parents)	• Developmental Disability (DD), or at risk of DD • No income criteria	• Medicaid • State • Federal • Third Party Payers	• No universal screening; some disabilities are not identified at birth. Some, such as autism or hearing loss, may manifest later. (See first comment) • Gap in referral process • Physicians are not well informed on low incidence disabilities. • Parents do not have access to a list of doctors with expertise in specific disabilities.	• EI for appropriate cases. EPSDT preventive care schedule includes developmental assessment at every visit and specifically recommends referral to • Gap may exist for children who are **at risk**[15] after EI eligibility ends (3 year olds) because they are not covered under Special Education Preschool Program [16] • Parents experience a sense of loss when their child enters the Special Ed system because that is child-focused versus the family focus in EI.

[15] "At risk" applies to children who do not have a diagnosed/identified disability, but who, because of environmental limitations or biological conditions in their early life, have the potential for developmental delay.

[16] Massachusetts' eligibility criteria for EI which are set by DPH, are broader than Special Ed's preschool in most school districts; this causes the gap for some 3 year olds. Children who are at risk of developmental delay experience significant impact that results from this difference as do children with mental health problems. For example, an asymptomatic, HIV positive 3 year old whose parents live at poverty's edge, may not meet the special ed eligibility criteria or Head Start's financial eligibility criteria. This creates a gap in day care because that child's parents probably cannot afford the costs associated with programs in the community.

CASE MANAGEMENT/SERVICE COORDINATION: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
(Department of Public Health DPH): Children with Special Health Care Needs (CSHCN) Family and Community Support Program				
• Direct and Indirect • Hospital Discharge Staff • SSI eligibility • Word of Mouth	• Chronic or fatal illness; • significant functional disability; • Kaileigh Mulligan (Medicaid) Home Care[17] enrollees • children on SSI	• State • Federal	• Eligibility criteria (children who do not meet functional criteria or have an identified need for voluntary service coordination, or if parents do not seek case management, fall through the cracks). • Benefits fragmented (service coordination is in one place, funding (Medicaid) is in another). • Some state services are not income dependent (service coordination) while other services depend on insurance.	

[17] The Kaileigh Mulligan program is a Midicaid funded benefit. The child's Medicaid eligibility is not based on the parent's income; intensive, ongoing medical needs, which put the child at risk of institutionalization are the basis for eligibility for Medicaid under the Kaileigh Mulligan program. Cost of home care may not exceed that of institutional care. Care equal to the level provided in an institution must also be provided at home.

CASE MANAGEMENT/SERVICE COORDINATION: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Indirect - parent calls DMH site and asks for case manager* [18] *See first bullet under Barriers.	Serious emotional disturbance, need for a service provided by DMH, problem expected to last at least one year, no medical entitlement or insurance or other agency responsible for and able to provide appropriate services.	• State • Federal	Services are very limited because of the following: • Most parents probably contact their pediatrician rather than DMH when behavior problems appear in this age group. Physicians may not recognize the problem. Communities also have the view that very young children do not have psychiatric disabilities. • Standardized screening and assessment tools are not widely utilized. .	▪ Service is remedial rather than preventive. ▪ Long wait lists for case management. Those waiting prioritized according to need.

[18] Although few children under age 3 are serviced through DMH, as most of that is covered through Early Intervention, direct treatment services are available. DMH community based services, including outpatient for the child and family, individual and family flexible support (including in-home interventions and consultation with collaterals) is available for children who meet DMH eligibility criteria and who are prioritized as clients.

CASE MANAGEMENT/SERVICE COORDINATION: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR) **Family Support Program (A 2176 Home and Community Based Services Medicaid Waiver Program)**				
▪ Direct ▪ Indirect	Diagnosis (federal definition) of developmental disability (DD)	State	• Services subject to appropriations. • Current estimates of prevalence have been changed in recent years to about 1.5% of the population for MR/DD, and about .8% for MR only. Using that percentage and the estimated population of Massachusetts for 1999 at 6.2 million, the estimated number of people with MR (and not DD) would be about 50,000. Since DMR now serves 30,000 (FY 2001), the difference of 20,000 would appear to be unserved. These numbers are only estimates of prevalence and not actual incidence statistics. In addition, not all people with mental retardation seek services through the Department.	• Service coordinators are generic; they function as the community connection for a family. • At this age a child with developmental disabilities is served through the Early Intervention (EI) program; however, families who require more supports than DPH offers transfer to DMR. • After age 3 children who have a documented developmental disability may qualify for services through Chapter 766 and thus receive them through their local education agency (LEA) in concert with DMR.

CASE MANAGEMENT/SERVICE COORDINATION: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB)				
Referred by ophthalmologist or optometrist to MCB's Central Registry. MCB contacts family and assigns a counselor.	Registered as legally blind	State		• MCB provides mostly case management and purchased services which cover consumers through age 13. Other service programs are available to legally blind youth and adults. • MCB also provides case management for blind children who are eligible for the Kaileigh Mulligan Program.

CASE MANAGEMENT/SERVICE COORDINATION: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Commission for the Deaf and Hard of Hearing MCDHH				
▪ Direct ▪ Indirect	Identified hearing loss	State	• Limited funds for staffing, which results in less than complete outreach since current staff cannot handle an increased load. • No dollars for purchase of services. • No mandated registry for children with hearing loss so parents may never hear about available services.	• Direct service to families through case managers who can provide specialized information about effects of hearing loss and specialized resources, assistance in understanding communication options, information regarding assistive technology, assistance in developing service plans and linkages with other parents and children. • Collaborative service is provided by MCDHH in technical assistance and training of other agencies which provide direct services[19]

[19] MCDHH's case management includes such functions as: cross-agency service coordination, technical assistance in developing service plans, and referrals to other agencies.

CHILDCARE: BIRTH TO AGE 6				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Office of Child Care Services - Subsidized Child Care Services				
Indirect (referred through either DSS or DTA)	Based on eligibility criteria of referring agency	▪ State ▪ Federal	▪ Income - i.e. families may be just over the income criteria, and not qualify for a subsidy. ▪ Wait lists	• Subsidized childcare services are limited to the number of available vouchers or contract slots to income-eligible families. • Income eligibility criteria for families of children with disabilities is greater than for families with non-disabled children.

INFORMATION AND REFERRAL (I&R) SERVICES: BIRTH TO AGE 6				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
Department of Public Health (DPH) Early Intervention (EI) Program				
"Child Find"[20] identifies children and families and makes referrals which are both direct and indirect	Evaluation by a multi-disciplinary team determines disability or at risk (both biological and environmental) of developmental delay.	▪ Federal ▪ State ▪ Insurance (state plans)		EI core team functions as Information and Referral (I & R) resource; provides link between family, program, and community services. [21]
Department of Public Health (DPH): Children with Special Health Care Needs (CSHCN) Family and Community Support Program				
Direct Indirect (word of mouth)	Multiple disabilities and/or chronic illness including Kaileigh Mulligan Home Care enrollees and children on SSI	▪ Medicaid ▪ Private Insurance ▪ CommonHealth		I & R provided through case management

[20] "Child Find" is a comprehensive statewide system that coordinates the various State agencies responsible for administering services (education, health and social) to identify all infants and toddlers in the Commonwealth who are eligible for services under the Early Intervention Program.

[21] While the Early Intervention Program does provide I & R as part of service coordination, the bulk of the program's dollars pay for services.

INFORMATION AND REFERRAL (I&R) SERVICES: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB)				
Direct - referred by physician or optometrist who makes diagnosis.	Certification of legal blindness	▪ State ▪ Federal		I & R provided through case managers who act as link to other agencies.
Department of Mental Retardation (DMR)- Family Leadership Program				
Diagnosis of disability at birth, SSI eligibility, or diagnosis of developmental disability (DD).[22]	Diagnosis of MR/ DD	State		This is primarily a support program, but also provides I & R on a rolling basis and is limited. Program is conducted 2-3 times in a 3-6 month time period
Department of Mental Retardation (DMR)				
Same as above	Same as above	Same as above		I & R is available to all families who contact DMR or its family support vendors.

[22] Developmental Disability (DD) is defined in Section 102 (8) of the Developmental Disabilities Act of 1994, as a severe, chronic disability (mental, physical or a combination) which occurs and is manifested between the ages of 5 and 22. It is likely to continue indefinitely, results in substantial limitations of 3 or more major life activities and reflects an individual's need for interdisciplinary supports.

INFORMATION AND REFERRAL (I&R) SERVICES: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Direct - DMH site office.	None. Service is available to any person concerned about emotional and behavioral problems in children.	State		I & R is available to all families who contact DMH site offices, community providers, or DMH website. It is also available through parent support groups.
Office of Child Care Services (OCCS) :Child Care Resource Agencies				
Direct	Open	Federal (block grant) State	None	▪ Enhanced services are available for families of a child with disabilities. ▪ Families are supported in accessing appropriate childcare in the community.
MA Commission for the Deaf and Hard of Hearing (MCDHH)				
Direct	Identified hearing loss.	State		• I & R is provided through a specialist and a regional bilingual case manager. • Special attention is given to assisting parents to become informed about communication options and assistive listening devices.

PERSONAL CARE ATTENDANT SERVICES: BIRTH TO AGE 6				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Division of Medical Assistance (DMA)				
Direct - services are accessed through provider agencies.	A child must be Medicaid- eligible and service must be medically necessary.	• Federal • State		
Department of Public Health (DPH): Kaileigh Mulligan Home Care Program				
Division of Medical Assistance (DMA)	• 18 years or younger • Child must meet Social Security disability standards. • Child must have intense medical needs that require home care equivalent to that provided in a pediatric hospital or nursing facility. • Child must meet income eligibility requirements	• Mediciad • Federal • State	• Limited to severely disabled children. • Prior authorization may be required.	• Program is an entree into the Medicaid system. Once eligibility is determined, a child is eligible for all Medicaid benefits.. • Eligibility determination is not made on the basis of the parent's income; the child may have assets that do not exceed those of a child who lives in an institution. • Non-medical services which are required for a child to live at home are not covered (e.g. respite, ramps, etc.).

PERSONAL CARE ATTENDANT SERVICES: BIRTH TO AGE 6 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB) Kaileigh Mulligan Home Care Program				
Division of Medical Assistance (DMA)	Determination of legally blind and eligibility criteria listed above.	Same as above	Limited to severely disabled children who are also registered as legally blind. (See above for additional barriers.)	See above.

PRESCHOOL/EARLY EDUCATION PROGRAM for CHILDREN FROM 3 TO AGE 6				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
Department of Education (DOE)				
Direct Indirect[28]	An evaluation process determines the need for special education.[29]	Federal State	• The at risk 3 year old who has no identified disability does not qualify for special ed.[30] • Some children who are identified do not receive appropriate assistance; for ex., a child using ASL as a primary language may not be placed in a peer group or with a teacher who can communicate with him/her. This may cause further developmental delay. • In some cases cross-agency service coordination is limited. This may result in assumptions about a child based on the services that are specific to the agency that is delivering them. • Interfacing between agencies and municipalities are not coordinated.	There may be a significant number of children who are at risk who are not being covered by EI services and, therefore, are not referred to preschool (see footnote #16).

[28] Each school district is required to make an effort to identify children who need special education by examining annual registration forms which request information about recent medical examinations and other information that would be relevant to a need for special education. (Registration and relevant information are optional). Services are also accessed by outreach through orientation session; kindergarten screening at a parent's request; and physical exams required by DPH for entry into the public school system.

[29] See Special Education Regulations, Massachusetts Department of Education, January 2001, 603 CMR 28.04:Referral and Evaluation.

[30] The evaluation process may determine an at risk 3 year old ineligible because s/he has no identified disability which qualifies for special education services in preschool programs. While there are state subsidized childcare programs, parents may not know how to access them after leaving the EI system (or if they have never been in the EI program), or they may not be able to afford a co-pay if eligibility in those programs is based on a financial criteria.

PRESCHOOL/EARLY EDUCATION PROGRAM for CHILDREN FROM 3 TO AGE 6 (continue)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
			• Community Partnerships for Children, a statewide organization (there are 168), serves children from 3-5. It originally started as a program to serve low income and "at risk" pre-schoolers, but eligibility has been changed and now requires that parents be working. Some funds are still available to serve "at risk" children whose parents are not working, but that funding has not increased since FY '93. Consequently a gap exists between what parents can afford and what is available to them. • Reimbursement mechanism Municipal Medicaid, the funding source for rehab/medical services provided to children with special needs, reimburses an average amount, per child, per week, based on a funding formula. These funds go back to the cities' and towns' general funds, not to the school system's budget. This may mean that schools are not fully reimbursed for the costs of providing those services. While this does not appear to be a disincentive to providing the necessary services, it often causes resentment at the local level in terms of school budgets. Special education funding cuts effect preschool programs.	

RESPITE CARE: BIRTH TO AGE 6				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR)				
Open	Diagnosis of MR/DD	State	• Limited; home based • Triage; family with greatest need prioritized	• Includes both facility and home based. • Demand severely outweighs the resources.
Department of Mental Health (DMH)				
Indirect: services authorized by case manager or a family's flexible support provider.	Must meet DMH eligibility criteria and be a DMH client.	State	Respite providers are difficult to find.	• From birth to age 3 respite care is provided through DPH. • From age 3 – 19, respite services are delivered under Individual and Family Flexible Support or a generic respite code. .
Department of Public Health (DPH) (in-home)				
Direct Indirect	Chronic or fatal illness. Significant functional disability and severe family need.	Federal State	• Very limited funds • Limited target group	No outreach because funding is so limited.
MA Commission for the Blind (MCB)				
Direct (MCB referral)	Registered as legally blind and financial criteria.	Federal (Title 20 Funds)	Very limited	Respite services may be cost-shared with DPH, DMR and DMH.

APPENDIX B

TABLE OF SERVICES FOR CHILDREN, ADOLESCENTS, AND YOUNG ADULTS FROM AGE 6 TO AGE 22

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Referred by DPPC	DMH client who is over 18.	State	• Abuse investigations are internal. DMH investigates its own contractors which could preclude objectivity in certain circumstances.	• Children under 18 are covered by DSS. • Neglect, which may be early abuses not covered under DPPC abuse referrals.
Department of Mental Retardation (DMR)				
Referred by DPPC; and cases under 115 CMR 9, the main DMR investiga-tion regulation.	DMR client who is over 18. Under 18 years of age is the responsibility of the Department of Social Services (DSS)	State	• Abuse investigations are internal. DMR investigates its own contractors which could preclude objectivity in certain circumstances. • There is oversight authority vested in DPPC to monitor/review ALL investigations. Additionally, the new MOUs (Memorandums of Understanding) with the District Attorneys now ensure that the most serious allegations (felonies) will be investigated by law enforcement professionals. Lastly, the appeals process continues to be a mechanism to review the quality and objectivity of a DMR investigation.	• Neglect is not covered under DPPC abuse referrals.

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Disabled Persons Protection Commission (DPPC)				
Direct Indirect (A 24 hrs/day hotline exists for reporting abuse). After report is made DPPC screens it, may investigate or refer to appropriate state agency.	Disabled adult (ages 18 - 59) who, as a result of the disability, is totally or partially dependent on others to meet daily living needs.[31]	State	• Statute defines abuse narrowly, so no jurisdiction over (most) neglect (abuse under 19C includes "omission" which is defined as the failure to do that which ought to be done) none over financial exploitation, or abuse/neglect inflicted by parties other than "caretakers".[32] Thus DPPC cannot assist in some cases where adults with disabilities are at risk or have suffered harm. • Statute did not envision that DPPC conduct all investigations, but rather that it refer many to DMR, DMH, and MRC, depending on disability of alleged victim. Thus DPPC does not have complete control over all investigations, and in substantiated cases cannot enforce recommendations to the 3 state service agencies regarding protective services and other follow-up activities. • DPPC depends on information from other agencies to monitor referred cases.	• Jurisdiction is extremely limited - i.e. abuse only; no protections from neglect (see definition under "Barriers") or financial exploitation. • Statute covers only ages 18-59, and only if not in facility (e.g. nursing homes) covered by DPH investigations. Reporters of allegations involving alleged victims not covered by DPPC are referred to DSS, Elder Affairs, DPH, police, etc. • State agencies responsible for protective services may have a hard time finding services for people unlike their "usual" consumers. • DPPC has the authority to redo an investigation if it is not satisfied with that done by the referral agency.

[31] Children, people in nursing homes, and individuals in the elder care system are covered under other systems.

[32] Abuse under 19C includes "omission" which is defined as the failure to do that which ought to be done.

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Disabled Persons Protection Commission (DPPC) (continued)				
			• Insufficient funds to do adequate public education and trainings on indications of abuse and to translate materials into most common foreign languages	
MA Rehabilitation Commission (MRC)				
Indirect-DPPC refers complaint regarding person with physical disabilities to MRC.	Individual must have a severe physical disability and be between the ages of 18 and 59.	State	• Individuals who have been severely injured as a result of domestic violence may be unable to find accessible shelters or other alternatives. • Protective services are limited to abuse by caregiver; abuse by someone other than caregiver is outside of MRC's jurisdiction. Protection from neglect is not included in these services.	

CASE MANAGEMENT/SERVICE COORDINATION: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Education (DOE)				
• Direct • Indirect	Student is deemed appropriate for special ed services after an evaluation to determine if the student has a disability and if the disability affects the student's ability to make effective progress in school.	• Federal • State • Local	• Children who do not meet special need criteria may fall into a gap. • More professional development is needed (both pre-service and in-service) in working with students who have low incidence disabilities. • The lack of human service agency participation in the development of transition planning leaves students poorly prepared for leaving school. Waiting lists for services provided by those agencies reflect this lack. • There is a lack of consensus about the least restrictive environment (LRE) for children who are deaf and hard of hearing. Children face service gaps that result from this lack in school. • No state approved or adopted set of standards or certification process exists for educational interpreters. • Assistive listening devices for hard-of-hearing children are inadequately funded at the local level, often due to lack of information at the local level about these devices.	• **Case management is not a service provided by DOE.** It appears in this category because coordination of special education and related services for children with special needs are delivered through an Individual Education Plan (IEP) which states the services needed by a student. **The Special Education Administrator** is responsible for ensuring coordination and delivery of IEP services.

CASE MANAGEMENT/SERVICE COORDINATION: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Education (DOE) (continued)				
			• The quality of services to children with low incidence disabilities varies. Young children with autism, for instance, usually require a high intensity of services. These services are often hard to find. Early delivery of these services may be vital to later development. • Schools are writing **504 plans** for students with disabilities rather than **766 plans.** School systems have no guidelines or training in the differences between the two plans. Students may receive **inadequate or inappropriate services** as a result.	
Department of Mental Health (DMH)				
Indirect: parents for those under 18, and individuals 18 and older, apply for DMH eligibility.	Children who have a serious mental illness, behavioral problems, and/or a serious emotional disturbance. Eligibility is not limited to children who are in	• State • Federal	• Not enough case managers. • Though each client is supposed to have a case manager, funding constraints limit all case management services to those who most need assistance, i.e. children transitioning from hospital and residential care to home or a less intense level of care, those who receive services from multiple sources that require coordination, and families requiring intensive support and advocacy services.	• DMH serves approximately 10,000 children/yr. In FY'01, 1916 children received case management services. These services require a formal enrollment (not all children receive those services). • DMH regulations call for each DMH client to have a case manager, but there is not sufficient funding for this to occur.

CASE MANAGEMENT/SERVICE COORDINATION: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH) (continued)				
If eligible, the Area office assigns case managers based on client need.	residential facilities or psychiatric hospitals, but they are a priority.			• Case managers develop the child's individual service plan with the family, coordinate service delivery, assist in obtaining non-DMH services, provide intensive support and advocacy, and monitor client progress. The goal is to assure clients receive the services they need to maximize their functioning.
Department of Mental Retardation: (DMR) Family Support Program				
• Direct • Indirect (via administrative office) • Autism support centers are accessed directly	Diagnosis (federal definition) of developmental disability (DD)	State	• Services subject to appropriations. • Services differ region to region; therefore, a client cannot be served if they live in the area where a beneficial project is not available. • Lack of available home-care resources	• Service coordinators are generic; they function as the community connection for a family. • Children, adolescents and young adults qualify for services through Chapter 766 and receive services through their local education agency in concert with DMR. • Children between the ages of 16-21 who drop out of school no longer receive Chapter 766 services. As a result, a decrease in services usually occurs. Family support services are still available, however.

CASE MANAGEMENT/SERVICE COORDINATION: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation: (DMR) Family Support Program (continued)				
				• Some case management is delivered through family support providers in the area offices, but many families prefer to coordinate their own services based on individual needs, through the Flexible Funding Support Program.
Department of Public Health (DPH): Division for Children with Special Health Care Needs in the Bureau of Family and Community Health				
• Direct • Indirect (Hospital Discharge, SSI Eligibility, Word of Mouth, Parent)	Child must have chronic medical condition or disability expected to last more than 12 months and an identified need requiring staff intervention. **(Note: Eligibility for this service starts at age 3).**	Federal	• Eligibility criteria for service coordination - i.e. some children may fall through the cracks. • Benefits, funding sources and services requiring coordination care are all located in different agencies. • Many services are dependent on insurance eligibility criteria. • Limited staff and limited language capability.	• No direct services are provided • Two types of case management exist and are defined by the length of time involved in resolving needs: (1)limited (3-6 months) and (2) extended. • Individual Family Service Plan (IFSP) is family defined and driven. • Case manager assists total family in resolving needs. Children under 18 and their families are served in 3 ways: Information and Referral, more in depth technical assistance and limited and extended service coordination.

CASE MANAGEMENT/SERVICE COORDINATION: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Public Health (DPH): MassCARE				
Direct	HIV infected and affected children and adolescents and their families at 6 community sites statewide.	Federal	• Language capabilities may be limited at different sites. • Support services vary (e.g. transportation, child care, counseling, etc.).	• Case management is linked to primary care provider who works in collaboration with HIV specialist to make community-based HIV care available at all times. • Five out of 6 sites have a case manager for whom Spanish is the primary language. • Case management is available to the whole family.
MA Commission for the Blind (MCB) 1. General Case Management				
Direct (referred by physician or optometrist who makes diagnosis of legal blindness).	• Registered as legally blind and under age 14; after that age they are referred to MCB's Vocational Rehabilitation (VR) program	State	• Funding is extremely limited. • Limited resources may provide barriers to receiving recommended services.	• If a child has other severe disabilities as well, MCB is the lead agency for providing case management services. • MCB provides mostly case management services and purchased services. • MCB provides an individualized transition plan for students graduating from special education. Effective implementation is contingent upon ongoing collaboration between school and human service agencies.

CASE MANAGEMENT/SERVICE COORDINATION: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB) 2. Turning 22 (Chapter 688)				
Direct (referred by physician or optometrist who makes diagnosis of legal blindness).	• Young adults up to age 22 who are legally blind and who may have a severe disability (planning usually starts at age 16).	• State • Local	• Funding is extremely limited. • Limited resources may provide barriers to receiving recommended services.	• If a child has other severe disabilities as well, MCB is the lead agency for providing case management services. • MCB provides mostly case management services and purchased services. • MCB provides an individualized transition plan for students graduating from special education. Effective implementation is contingent upon ongoing collaboration between school and human service agencies.
MA Commission for the Deaf and Hard of Hearing MCDHH				
Direct	Deaf and hard of hearing children and their families.	State	• Large caseloads • Staffing shortage • Very limited funding • Lack of awareness among providers about special needs. • Insufficient specialized programs.	• Provides range of case management services such as: information, referral to specialized resources, cross-agency service plan development, assistance to family and client in ed plan development, advocacy, ADA-related information and counseling to consumer and family regarding disability issues. • Provides information, technical assistance and training to education agencies.

CASE MANAGEMENT/SERVICE COORDINATION: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Rehabilitation Commission (MRC: Independent Living Division (Statewide Head Injury Program)				
• Direct • Indirect	• Externally caused head injury	• State	• Wait lists • Waiting periods • Limited funding	• The Statewide Head Injury Program (SHIP) is housed in the Independent Living Division • SHIP provides case management services

CRISIS INTERVENTION SERVICES: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Accessed through Area Offices or Emergency Services Programs.	Available to anyone in psychiatric crisis who cannot access such service through insurance.	• State • Federal	• Limited funding	
Department of Mental Retardation (DMR)				
Direct (via the administrative office)	Diagnosis of mental retardation	State	• Funding - intensive, costly supports are needed when families are in crisis. Funding may limit the number of families served as well as the intensity of the supports delivered. • Time limited	• DMR is moving from a crisis response intervention to family supports which are preventive. • There is a new component to the department's Flexible Family Support Program that allows supports to be enhanced and increased when necessary. The program, which is vendor operated and regionally based, serves about 100 families (on a rolling basis) annually in each region. In statewide total, DMR has capacity for more than 500 families. • Management of these services varies from region to region.

DAY PROGRAMS: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Indirect: must be authorized as part of Individual Service Plan or by Area Office.	▪ Serious emotional disturbance. ▪ Limited to clients who have met DMH eligibility criteria, but may, at Area Office discretion, be authorized for up to 60 working days for non-clients. ▪ Age limit is 19 years.	• State • Federal • Medicaid	• Age limit (19 years old).	• Programs generally operate after school, evenings, weekends, and vacation periods. • School is responsible for educational services during the day. • There is one full day program in which the school provides the educational piece.
Department of Mental Retardation (DMR): Education Advocacy				
Direct: Administrative Office	Diagnosis of mental retardation or development disability	State	• Limited funds regionally • Some limited funds to support special after school programs – i.e. autism.	DMR provides flexible funds to support education advocacy and training to families to insure education needs are provided. Each region has an education co-director (contract) to provide stipend and parent/ed trainings and increase parent knowledge.

HEALTH CARE **Publicly funded health insurance and benefits programs**				
DEPARTMENT OF PUBLIC HEALTH: CHILDREN'S MEDICAL SECURITY PLAN				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
Direct	▪ Children under 19 who are not enrolled in Medicaid ▪ Sliding fee scale based on family size and income applies to premium payments ▪ Co-payments may be required	▪ State ▪ Federal	▪ Prescription coverage limited to $200/child/year ▪ Co-pay required for prescriptions and some benefits	Plan administered by private health insurance company
DIVISION OF MEDICAL ASSISTANCE: MASSHEALTH				
Direct (through MassHealth Enrollment Center)	▪ Disabled (receiving SSI/SSDI) ▪ Limited income and assets ▪ Adults without dependent children who have long term unemployment (one year) ▪ Children under 19 in families with income up to 200% FPL ▪ Pregnant women up to 185% FPL ▪ Family with children under 19 and incomes up to 150% FPL ▪ Family member living with children under 19 with disabilities ▪ Working, disabled adults over 19 ▪ Non-working disabled adults with income at or over 100% FPL	▪ State ▪ Federal	▪ System is complex and can be confusing (many types of coverage and different eligibility standards) ▪ Prior Authorization for certain services, i.e. durable medical equipment (DME) and personal care attendant services require members to wait for approval ▪ Delays in getting providers of DME to deliver product, particularly when equipment is customized ▪ Reimbursement model, due to interweaving of payers, can be confusing to consumers	MassHealth includes various types of coverage, different eligibility criteria for a wide and diverse group of individuals

HEALTH CARE (continued) Publicly funded health insurance and benefits programs				
DIVISION OF MEDICAL ASSISTANCE: COMMONHEALTH				
Direct (through MassHealth Enrollment Center)	• Children under 19 who are disabled • Working, disabled adults over 19 • Non-working disabled adults with income at or over 100% FPL	▪ State ▪ Federal	▪ No income limit, but if income exceeds a certain amount a premium may be required or a one-time deductible. ▪ Meeting deductible may result in incurred debt for individuals whose income is too high, but whose necessary medical expenses are also high. For example, a person who works and whose income is just over the limit for the MassHealth Standard Program, may require PCA services that need to be paid when services are delivered.	Children under 19 who are disabled may be eligible regardless of income.

HEALTH CARE (continued) Publicly funded health insurance and benefits programs (continued)				
DIVISION OF MEDICAL ASSISTANCE; KALEIGH MULLIGAN HOME CARE FOR DISABLED CHILDREN PROGRAM (KMHCDC)				
Direct	Children under 18 with a disability who require a level of care equivalent to that provided in a hospital or nursing facility in accordance with MassHealth regulations	▪ State ▪ Federal	Definition of severe disability is very narrowly defined.	▪ A MassHealth Program ▪ Cost of caring for child at home may not exceed cost of institutionalization ▪ Parent's income not a factor but the child's income and assets would be counted ▪ Program also available to children who are enrolled at MA Commission for the Blind and who meet ▪ KMHCDC eligibility guidelines

OUTPATIENT REHABILITATION AND COUNSELING: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Direct	None. DMH funds when child or family cannot be covered through public or private insurance.	State Federal.	Wait lists for services due to general staffing crisis in human services and growth of private practices.	• This is not **primarily** a system geared to providing ongoing supports to families. Outpatient services provide diagnosis, evaluation and treatment for mental health disorders. • DMH funding for outpatient has decreased as a result of mental health insurance parity and increased funding for preventive mental health services in public insurance programs.

RESIDENTIAL TREATMENT SERVICES: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
▪ Indirect: through case manager. ▪ May be referred from any source, inpatient care, continued inpatient care, other residential programs or the community.	Severe Emotional Disturbance; must be DMH client and authorized for this level of care.	• State • Federal • Medicaid • Local Funds (Education funds the school portion of the program).	• Limited facilities • Age limits – i.e at 19 an adolescent is technically considered an adult in the DMH public mental health system. Young adults who have aged out of the system and do not meet the mental health criteria[33] for adult services, but whose independent living skills are not yet adequate, fall into a gap which is potentially far more disastrous for them and society than the gap facing children from 3 – 6 (also see second bullet under Comments). • A funding request to create 35 slots addresses this gap and was included in the FY'02 budget, still pending as of October 2001.	• Most children who need residential treatment at this age are served by DSS because their problems generally stem from family issues rather than mental illness. • DMH's statewide programs serve a low incidence but high-risk population. Facilities include 1 20-bed hospital program, 2 clinically intensive residential treatment programs serving 24. There are 5 intensive residential treatment programs (IRTPs) serving 75, 2 specialized Behavioral Intensive Residential Treatment programs with a total capacity of 30 for adolescents in DSS custody, and 3 hospital programs for up to 48 adolescents. • A range of community residential services are available in each DMH Area, including provision of residential level supports in the child's home in some locations. • Some young adults who technically have aged out of DMH's children's services continue to be served because they are a social danger and there is no other place for them to go.

[33] These young adults, unless they are committable to a DMH hospital, may become homeless because they have no place to go for services.

RESIDENTIAL TREATMENT SERVICES: AGE TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR)				
• Through the local education agency (out of district placement[34] • Through DSS placement (very few placements occur through this avenue).	Diagnosis of mental retardation	Schools – state and local funds	• Not enough funding for the DMR/DOE program, which is successful, and cost effective. Lack of sufficient funds impacts the ability to support families and children in their home community. • Wait list due to funding limits	• An Inter-agency Service Agreement (ISA) between DMR and DOE focuses on (a) preventing residential placements and (b) returning children who are currently in those placements to their families. The average annual cost of prevention is $25,517, and the average annual cost of a return from a residential placement is $36,829. There are now 210 children in this program. • This program has a 96% success rate. • The above prevention programs have significant participation. Over 210 districts have participated in this project.

[34] See Special Education Regulations: Massachusetts Department of Education, January 2001, 603CMR 28.04 – 28.05..

RESIDENTIAL TREATMENT SERVICES: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Education (DOE): Educational Services in Institutional Settings (ESIS)				
Direct - i.e. through a human service agency	Local school districts Teams determine eligibility for special education.	DOE component funded by state dollars.	This is not a service that is accessible to everyone. An individual must be placed by a state agency in an institutional program for which ESIS provides special education.	• State Agency-run residential programs, provide treatment in an institutional setting. Special Education provides the education component **only** if a child has special education needs. • The current trend is to open more sites. The ESIS budget will need to expand to adequately cover the creation of new programs. • Children may change sites so there is discontinuity in education. • DOE has no role in an institutional treatment placement, because residential placement priorities are determined by the human service agency making the placement. • Education services are good, but limited funds affect provision of specialized services by ESIS; school district Teams determine if additional services will be funded. • Average number of students served daily in 1995 - 780. • Program sites in 1995 - 65.

RESIDENTIAL TREATMENT SERVICES: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Public Health (DPH): **The Medical Review Team (MRT); Residential Pediatric Nursing Home Care (Birth to 22 years of age)**				
Direct referrals	Multiple disabilities, requiring 24 hour skilled nursing care and/or intensive therapeutic treatment with a cognitive functioning level at 12 months or below.	Private insurance and Medicaid pay for pediatric Nursing Homes.	Lack of availability	• The MRT only determines eligibility and certification for pediatric residential nursing homes for children through age 21. **It does not do placements.** The role of DPH is to convene the Team, a multi-disciplinary, interagency group. • Once eligibility is determined, the family formally applies for admission to one of 4 privately owned pediatric nursing homes. If a child does not enter a nursing home at that time, s/he must be re-certified after 6 months. • Once a child is certified, families choose the nursing home to which they want their child admitted.

RESPITE CARE: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Health				
Indirect: services are authorized by case manager or a family's flexible support provider	• Must meet DMH eligibility criteria and be a DMH client. • Client must be between 3 and 19 years old	State	• Limited funds	Services funded through: • Individual Family Flex Support and under a respite • Programs contracted under generic respite code
Department of Mental Retardation				
• Direct • Indirect	Must meet DMR eligibility criteria and be a DMR client	State	• Limited funds	• Services funded through Flexible Family Support Program, which enables a family to spend funds directly on respite, or other services like summer camp or YMCA activities. • Families also have the choice of purchasing respite services through a vendor.
Department of Public Health				
Direct	Chronic or fatal illness. Significant functional disability and severe family need.	• Federal • State	• Limited funds • Limited target group	

RESPITE CARE: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB)				
Direct	Registered as legally blind	Federal	Limited	Respite services may be cost-shared with DPH, DMR and DMH.

SUPPORTED EMPLOYMENT: AGE 6 TO AGE 22				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Direct	• Under 19 years old. Will expand to 22 in FY'02. • Serious mental illness or emotional disturbance.	• State • Federal funds will also be used in FY'02.	• Supported Employment is very limited. • DMH relies on the school system (special education) to provide training for school to work. • Transition plan is included in the student's IEP, but program is not funded.	
Department of Mental Retardation (DMR)				
Direct	Diagnosis (federal definition) of Developmental Disability	State Federal	• Limited due to funding. • The interface between DMR and MRC has improved in recent years, but consumers would benefit from better service coordination. • Transition plans which are done in school, should include VR.	• Supported employment can now be billed under the Home and Community Based Services Waiver Program. • There has been an increase in the percentage of DMR consumers moving in to integrated employment settings.

SUPPORTED EMPLOYMENT: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB)				
Direct-MCB refers client to a state vendor.	Identified as legally blind, eligible for VR services and appropriate for supported employment services.	Federal	• People who are blind and have a secondary disability may not have long term funding sources. • Long term supports need to be identified preliminarily, but vendors are reluctant to do this because of funding/time limits. • Transportation.	At age 14, children are referred to the VR program where an array of services is available in preparation for employment to eligible individuals.
MA Rehabilitation Commission (MRC)				
Direct	Physical and/ or mental disabilities that present barriers to employment; person must also be able to benefit from VR services.	• State • Federal	• Time-limited funding (funding for job coach is limited to 18 mos.) • Priority given to consumers with "severe disabilities". • Transportation - lack of options, accessible vehicles, affordability, lengthy trips. System is geared to group travel and delivering employees to the contracting agency, not the work site. Clients with cognitive disabilities may need to be transported directly to the work site.	• Employers need to be educated about the need to provide reasonable accommodations, especially for those with mental illness. • The need exists to explore and develop more transitional employment entities.

SUPPORTED EMPLOYMENT: AGE 6 TO AGE 22 (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
MA Rehabilitation Commission (MRC) (continued)				
			• Employers do not understand issues related to people with disabilities (job coaches, reasonable accommodations such as flexible scheduling, etc.) and, therefore, are reluctant to hire. • Impairment related work expenses (IRWEs) such as a Personal Care Attendant (PCA) may be rejected because of SSDI income. • Supported Employment (SE) clients need to learn marketable skills that will allow them to sustain employment in an integrated, competitive work environment. • Lengthy waiting lists, long waiting periods.	

APPENDIX C

TABLE OF SERVICES FOR ADULTS

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Disabled Persons Protection Commission (DPPC)				
• Direct • Indirect (a 24 hrs/day hotline exists for reporting abuse). After report is made DPPC screens it, may investigate or refer to appropriate state agency. DPPC 24-hour reporting hotline is: 1-800-426-9009	Disabled adult (ages 18-59) who, as a result of a mental or physical disability, is totally or partially dependent on others to meet daily living needs.	State	• Statute defines abuse narrowly, so no jurisdiction over (most) neglect (abuse under 19c includes "omission" which is defined as the failure to do that which ought to be done) none over financial exploitation, or abuse/neglect inflicted by non-care givers. Thus, DPPC cannot assist in some cases where adults with disabilities are at risk. • Statute did not envision that DPPC conduct all investigations, but rather that it refer many to DMR, DMH, and MRC, depending on disability of alleged victim. Thus, DPPC does not have complete control over all investigations. Due to lack of funds, DPPC does not have staff to do all Chapter 19C investigations. • Victims of abuse, 60 years old and older, who live in DMR and DMH funded facilities, are not covered under Chapter 19C and EOEA does not provide oversight on these cases.	• "Care giver" is defined as a person or agency that is responsible for a disabled person's health or welfare in any day or residential setting (this can include a private home). • Statute covers only ages 18-59, and only if not in a DPH facility (e.g. nursing homes, rest homes, chronic rehabilitation facilities). Reporters of allegations involving alleged victims not covered by DPPC are referred to DSS, Elder Affairs, DPH, police, etc. • State agencies responsible for protective services may have a hard time finding services for people unlike their "usual" consumers (people who fall into gaps). • DPPC has the authority to redo an investigation if it is not satisfied with that done by the referral agency.

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Disabled Persons Protection Commission (DPPC) (continued)				
			• DPPC depends on information from other agencies to monitor referred cases. • Insufficient funds to do adequate public education and training on indications of abuse and to translate materials into other languages.	• Outreach, training, and education has increased significantly due to federal funding for an Abuse Prevention Project. • Coordination among agencies could save up to $1 million.
Department of Mental Health (DMH)				
• Indirect - referred by DPPC • Direct	• DMH client who is over 18, or any client who has been terminated within the last 6 months, or, if in the opinion of the Commissioner it is in the public's.	State	• While agencies need authority to conduct investigations and implement an immediate correction, for credibility, the primary investigation should rest with an outside agency. Under the existing system, most abuse investigations are internal (DMH investigates its own contractors). • Improvement could be made in sensitivity to cultural, linguistic or ethnic minorities in pursuing or following up investigations.	• Neglect, which may be early abuse, is not covered under DPPC abuse referrals. • DMH's Human Rights program is separate from the Office of Internal Affairs. Human Rights officers act as advocates for clients and help resolve human rights issues and to educate staff on those rights. Each program, hospital and area office has human rights officers. The Office of Internal Affairs conducts

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH) (continued)				
	interest to investigate an abuse complaint. • In the case of an individual who is not a DMH client, but is referred by DPPC because disability is mental illness DMH does the investigation.			investigations once a formal complaint (relating to action which is dangerous, inhumane, or illegal) has been made. • DMH has general authority to investigate illegal, dangerous or inhumane incidents occurring in programs funded or operated by DMH. In programs licensed by DMH such as a hospital psych unit the investigation is done by the Office of Internal Affairs.
Department of Mental Retardation (DMR)				
• Indirect: referred by DPPC • Direct : complaint may be reported to the senior investigator in one of 5 state regions by DMR staff. all of	DMR client who is over 18.	State	• Same as above • Screening process needs refining to eliminate cases which do not meet abuse criteria. • There are not enough mechanisms for determining various types of complaints. • Some cases are very lengthy and time consuming which slows processing	• DMR has a new Investigations Director, tackling these issues along with DPPC. DPPC oversight, Law enforcement deferrals. • DMR is working with DPPC to refine screening criteria • DMR is presently working with staff to improve performance on timelines. CORE training is ongoing.

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
whom are mandated reporters. After making determination, complaints are referred to Division of Investigation.			• The definition of "caretaker", as defined by Chapter 19C, may be unclear to state agency personnel in the field who are mandated to report suspected abuse. This ambiguity as to who actually qualifies as a caretaker may result in unreported abuse.	• An Office of Human Rights (OHR) exists within DMR which is operationally and conceptually separate from DMR's Division of Investigation. The OHR has a range of monitoring and other means for learning of questions or concerns about regulatory violations and tries to intervene before harm comes to an individual. It also performs the Commissioner's Review of restraint use and actively intervenes in specific cases to resolve irregularities as well as providing statistical data on the use of restraints statewide. The Division of Investigation focuses on abuse and related issues (e.g. suspicious deaths, criminal and illegal behavior).

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR) (continued)				
				The Blue Ribbon Panel finished its work and made numerous recommendations that are being implemented. One of them is the use of MOUs between DMR and other agencies.
Department of Public Health (DPH)				
• Direct • Indirect There is a 24-hour hot line	No eligibility requirement; only requisite is that a complaint must be relative to an institution which is licensed by DPH.	• State • Federal	None	• DPH has jurisdiction over all facilities that it licenses, whether public or private. • Investigators may be social workers, nurses, dietitians, or life-safety engineers. • If complaint is substantiated as a result of an investigation, it is filed. If serious, the facility is put on an enforcement track for oversight. • An appeals process exists for findings that are disputed.

ABUSE INVESTIGATIONS/PROTECTIVE SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Rehabilitation Commission (MRC)				
Indirect – Referred by DPPC, or community agency.	Individual must have a severe physical disability and be between the ages of 18 and 59. It is not essential that the person be an MRC client. (See comments)	State	• Individuals who have been severely injured as a result of domestic violence may be unable to find accessible shelters or other alternatives. Also, shelters do not have internal services that may be necessary to a person with a severe physical disability (for ex., PCA-like services). • Shelters may not have any services for people who are deaf, or if they do have one, staff may not know how to use it or the relay service. • It is difficult for a person with a disability to utilize a restraining order, particularly if the abuser provides personal care, because care and housing options are limited. Thus, abused individuals may take risks and refuse protection in order to remain home. • Often there is a lack of knowledge about the abuse statute (CH. 19C) among professionals other than ER physicians and VNA providers. • CH. 19C empowers an agency to do an abuse investigation; this may disempower a consumer who wishes to decline protective service investigation and follow up. • Protective services limited to abuse by caregiver.	• In the case of an individual with multiple disabilities, DPPC decides which agency should be assigned the abuse investigation. Immediate need of consumer is usually the priority. For example, a person who has severe physical disabilities and is suicidal will most likely be referred to DMH.

CASE MANAGEMENT/SERVICE COORDINATION: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Direct - a closed service which is only available to some DMH clients (see Eligibility criteria).	Eligibility is determined at area offices based on diagnosis of severe and persistent mental illness, a need for continuing care, and level of service needs.	• Medicaid • State • Federal • Private pay	• Waiting lists • Priority system and waiting lists may preclude some consumers from receiving case management services.	• Case management includes developing an Individual Service Plan (ISP) based on a comprehensive assessment of an individual's need. • Service provided to approximately 1/3 of clients. • Services for consumers with acute needs are paid by the Division of Medical Assistance.

CASE MANAGEMENT/SERVICE COORDINATION: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR)				
Direct (services provided through area offices).	Adults (18 years of age and older) who meet the DMR adult eligibility criteria (defined by American Assoc. of Mental Retardation) receive this service. Children who do not meet adult MR criteria when they turn 22, but meet DD eligibility[35] will be served only if they received supports prior to age 18.	State	• Individuals who become developmentally disabled after age 18 may wind up patching together necessary services from various state agencies with no overall coordinated service plan. • Case loads are high which often results in limited service. • Individuals served by the Family Support Program receive supports contingent on prioritization and annual appropriations of state funds.	• **Case management/Service coordination** is provided through Medicaid reimbursement • The Medicaid Home and Community Based Waiver funds a full range of community support **services** including transportation, employment programs, residential staffing costs and individual supportive living. • There is no waiting list for service coordination, but that fact does not ensure a consumer will be provided with the necessary services. For example, a consumer may have a service coordinator who identifies the need for a day program, but the waiting list for that service is very long and the consumer may be placed at the bottom of the list

[35] Developmental Disability (DD) is defined in Section 102 (8) of the Developmental Disabilities Act of 1994 as, a severe, chronic disability (mental, physical or a combination) which occurs and is manifested between the ages of 5 and 22. It is likely to continue indefinitely, results in substantial limitations of 3 or more major life activities and reflect an individual's need for interdisciplinary supports.

CASE MANAGEMENT/SERVICE COORDINATION: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR) (continued)				
				• Service coordination is also a part of DMR's Family Support Program. The goal of that program is to **support and empower** families as they determine their needs. Not all families use service coordinators from DMR's area offices, preferring, instead, to coordinate their own service needs with assistance, in many cases, from family support agencies. Some of the services provided in this program include, home modification, specialized equipment/supplies, respite, etc.
MA Commission for the Blind (MCB)				
Direct (referred by physician who makes diagnosis of legal blindness). Individual is then registered in a central registry and from there referred to one of 6 regional offices.	Registered as legally blind.	• Federal • State		• Case management and service coordination are functions of the direct service staff that consists of VR counselors, social workers and rehab teachers. If client is 18 - 59 years old and seeks employment, s/he is automatically referred to vocational rehabilitation (VR) and assigned to a counselor in his/her local area for service coordination. If employment is not the goal, then that individual works with a social worker. • Most services are free to consumers. Some purchased services are available only to individuals who meet a certain financial eligibility standard.

CASE MANAGEMENT/SERVICE COORDINATION: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB) (continued)				
				• Rehab teachers teach activities of daily living (ADLs) in the consumer's home; or in the case of VR clients, at the work site. • Information and Referral is provided through service coordination/case management.
MA Commission for the Deaf and Hard of Hearing (MCDHH)				
• Direct • Indirect	Consumers: Deaf, late deafened and hard of hearing individuals of all ages.	State	• Funding constraints result in: under-staffing; large caseloads; slower delivery of actual services than is desirable; limited outreach to the elderly. • No purchase of service dollars for gap consumers. • Insufficient funding to provide adequate training, I&R, technical assistance and advice re. policy development to providers (including state agencies)	• Bilingual case management includes: information and referral services; individual assistance/training to hard of hearing and late deafened consumers re. resources and technology; case management; service coordination and cross-agency service plan development; technical assistance and training to provider agencies; development of individual, comprehensive, total life needs service plans. • Provides cross-agency case management including Turning 22 (CH. 688). • Technical assistance provided to state and community agencies.

CASE MANAGEMENT/SERVICE COORDINATION: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
MA Commission for the Deaf and Hard of Hearing (MCDHH) (continue)				
			• who lack awareness about the needs of this population. • Insufficient specialized programs due to limited funding. • More service coordination and information/training needed for individuals who are hard of hearing or have become deaf later in life.	• Co-case management provided to all state agencies.
MA Rehabilitation Commission (MRC): Independent Living Division, Statewide Head Injury Program (SHIP)				
• Direct • Indirect	• Traumatic Brain Injury (TBI)	• State	• Waiting **list** is long • SHIP has no coma management services available for the individual or his/her family members. • Funding constraints limit services	• The Statewide Head Injury Program (SHIP) is housed in the Independent Living Division • SHIP provides case management services

DAY PROGRAM/DAY HABILITATION /DAY TREATMENT SERVICES: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
• Direct • Indirect	• Consumer meets DMH eligibility criteria; however, clubhouses are open referrals.	• Medicaid • State • Federal	• Services are fragmented - multiple agencies (e.g. DMH, DET and MRC) fund services which makes it difficult for consumers to move from one support to another. • Capacity is limited due to agency budget and funding limits that result in prioritization. • Lack of transportation limits access to programs, particularly in rural areas.	• Program includes supportive, treatment and rehabilitative services such as: clubhouse activities, short term psychiatric day treatment, skills training and supported employment. • Social clubs and clubhouses have open referrals; all other day programs operate under a closed system.

DAY PROGRAM/DAY HABILITATION /DAY TREATMENT SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR)				
Direct (referred by area offices)	Must meet American Association of Mental Retardation definition of mental retardation.[36]	• State • Federal	• Although there is a waiting list for program opportunities, there has been a major funding and support effort to address the waiting list during FY '98, '99, '00, and '01. The size of the waiting list is decreasing and increasing numbers of consumers are moving into integrated work settings. • All programs are not available in all regions. • Individuals with developmental disabilities who do not meet the AAMR definition, may be precluded from DMR adult day programs. They may be eligible for day programs in other agencies such as MRC's day programs (job development or supported employment programs). • Adults with a diagnosis of DD must meet Medicaid eligibility criteria to receive day habilitation services.	• Two programs are available: (1) **education and training** - focus is on pre-vocational skills training and education as well as day activities, and (2.) **employment supports** which include both sheltered workshops and supported employment.

[36] The American Association of Mental Retardation's (AAMR) 1992 definition of mental retardation is based on 3 criteria: (1) an IQ functioning level below 70; (2) significant limitations in two or more adaptive skill areas; (3) condition presents itself before age 18 (AAMR, 1992).

DAY PROGRAM/DAY HABILITATION /DAY TREATMENT SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Division of Medical Assistance (DMA)				
▪ Direct (referred by state agencies) ▪ Indirect (agencies and individuals outside of the state system)	▪ Individual must be 18 years old ▪ Diagnosis of developmental disability or mental retardation is required.	▪ State ▪ Federal		▪ Most clients are referred by DMR. ▪ Clients receiving day habilitation services have medical issues and require active therapies. Services are based on the client's ISP and their purpose is to teach individuals how to live in the community. ▪ Approximately 5346 individuals participate in this program.

HEALTH CARE **Publicly funded health insurance and benefits programs**				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
DEPARTMENT OF PUBLIC HEALTH: CHILDREN'S MEDICAL SECURITY PLAN				
Direct	▪ Children under 19 who are not enrolled in Medicaid ▪ Sliding fee scale based on family size and income applies to premium payments ▪ Co-payments may be required	▪ State ▪ Federal	▪ Prescription coverage limited to $200/child/year ▪ Co-pay required for prescriptions and some benefits	Plan administered by private health insurance company
DIVISION OF MEDICAL ASSISTANCE: MASSHEALTH				
Direct (through MassHealth Enrollment Center)	▪ Disabled (receiving SSI/SSDI) ▪ Limited income and assets ▪ Adults without dependent children who have long term unemployment (one year) ▪ Children under 19 in families with income up to 200% FPL ▪ Pregnant women up to 185% FPL ▪ Family with children under 19 and incomes up to 150% FPL ▪ Family member living with children under 19	▪ State ▪ Federal	▪ System is complex and can be confusing ▪ Prior Authorization for certain services- e.g. durable medical equipment (DME) and personal care attendant services – requires members to wait for approval ▪ Delays in getting providers of DME to deliver product, particularly when equipment is customized ▪ Reimbursement model, due to interweaving of payers, can be confusing to consumers	MassHealth includes various types of coverage for a wide and diverse group of individuals

HEALTH CARE Publicly funded health insurance and benefits programs (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
DIVISION OF MEDICAL ASSISTANCE: COMMONHEALTH				
Direct	▪ Children with disabilities under 19 ▪ Working, disabled adults between 19 – 64 ▪ Non-working disabled adults with income at or over 100% FPL	▪ State ▪ Federal	See above ▪ Meeting deductible may result in incurred debt for individuals whose income is too high, but whose necessary medical expenses are also high. For example, a person who works and whose income is just over the limit for the MassHealth Standard Program may require PCA services that need to be paid when services are delivered. ▪ At 65 a person who is not working must move into another coverage and, depending on income, may have to pay another deductible.	▪ A **MassHealth Program** ▪ No income limits or assets tests. Eligibility is based on income and may require enrollee to pay premium or one-time deductible. ▪ Working disabled adults aged 65 and over may stay in the CommonHealth program.

HEALTH CARE Publicly funded health insurance and benefits programs (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE**	**BARRIERS**	**COMMENTS**
EXECUTIVE OFFICE OF ELDER AFFAIRS: PRESCRIPTION ADVANTAGE				
Direct	▪ Age 65 or older ▪ Under age 65, have a qualified disability and income below 188% FPL ▪ Any individual enrolled in either The Pharmacy Program or The Pharmacy Program Plus as of March 31, 2001; individual must enroll by **April 1, 2002.**	State (Tobacco Settlement Funds)	Cost sharing provisions, even though graduated, can be a financial strain for individuals with disabilities (not eligible for MassHealth coverage) who may have very limited incomes, intermittent employment and additional out-of-pocket expenses associated with their disability (personal care attendants, for example). Prescription Advantage requires cost sharing in the following areas: ▪ Premium (graduated) based on annual household income ▪ Deductibles required (see comments regarding those with household incomes below 188% FPL).	▪ Medicaid pays premium for individuals and married couples with annual household income below 188% FPL ▪ State pays deductibles for individuals and married couples with annual household income below 188% FPL ▪ Mail service is available

HOMEMAKER SERVICES/HOMECARE ASSISTANCE: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
• Direct • Indirect	Determined at local site office based on diagnosis of severe and persistent mental illness, a need for continuing care and level of service needs.	• State • Federal	Prioritization may limit funding and/or those who receive services.	Services for some DMH clients may be delivered through MRC's Homecare Assistance Program if they meet MRC's eligibility criteria.
Department of Mental Retardation (DMR)				
• Direct • Indirect	Adult must meet criteria of the American Association on Mental Retardation.	State	• Homemaker services are an allowable expenditure under the Family Support Plan which is funded by state dollars. Any reduction in state appropriations could limit the array of services available in the Plan including homemaker.	To receive homemaker services, the need must be documented in a family's Support Plan and be consistent with the Family Support guidel

HOMEMAKER SERVICES/HOMECARE ASSISTANCE: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR) (continued)				
			• An adult who does not meet MR eligibility and whose developmental disability (DD)* occurred after age 18, will not be eligible for services. • Prioritization may limit funding and/or those who receive funds for purchasing services. • Some families who need services may be wait listed following initial contact and eligibility determination. Every effort will be made to accommodate the needs of the family through service coordination and family support programs. *DD occurs between the ages of 5 and 22.	
MA Commission for the Blind (MCB)				
• Direct • Indirect	Must be certified legally blind, have serious illness or injury, financially eligible and under 60 years old.	State	This service is provided only to those who meet eligibility criteria and who would be unable to remain at home if service were not provided.	

HOMEMAKER SERVICES/HOMECARE ASSISTANCE: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCE/S**	**BARRIERS**	**COMMENTS**
MA Rehabilitation Commission (MRC)				
• Direct • Indirect	• Individuals with severe physical or mental disabilities (18 - 59 years of age) who are at risk of hospitalization or institutionalization without these services. Eligibility is determined by in-home functional assessment and medical documentation supporting the need. • Income eligibility criteria must also be met. • Individual must live alone or with minor children under 17 years of age.	State	• Funding constraints limit the number of individuals who can be served. • While individuals with children under age 18 may now be considered eligible, services will only be provided for the adult and the needs of the children will not be met. For example, if meal preparation is required, it will be prepared only for the parent. If children are too young to prepare meals for themselves other arrangements must be made to feed them. • A child turning 18 will be considered an adult and the parent's eligibility will be affected. • While services are limited to 12 hours/week, the average is only 4 hours/week.	• Service coordination may be included in this program. • Homemaking services provided by agencies under contract with MRC or by individuals hired by the consumer through a contract with MRC. • Tasks consist of meal preparation, grocery shopping, laundry and light housekeeping. **Homemaker does not provide personal care assistance.** Individuals who need Meals on Wheels are referred to their local Independent Living Center.

INDEPENDENT LIVING SERVICES: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Commission for the Deaf and Hard of Hearing (MCDHH) Deaf and Hard of Hearing Independent Living Services (DHILS)				
Direct	• Self-identification as Deaf, late deafened or hard of hearing. • Parent/family members of child with a hearing loss. • Local/regional service providers in need of information and education regarding communication access.	• State • Some private grants through some provider initiatives	• Insufficient funding for adequate staffing, for delivery of services needed, and for purchase of services statewide which limits: skill training for Deaf in most regions, communication-related skills training for late deafened and hard of hearing, outreach in most areas for multi-cultural populations, the elderly, suddenly deafened, hard of hearing, and system change efforts in most regions. • No dollars for development of: ASL-accessible peer support system for substance abusers, parent training programs, peer mentor training and for cross-agency sharing of materials, staff training, and strategies.	• MCDHH contracts for DHILS services/programs in 10 state regions. Services delivered by a multi-service center for the Deaf, late deafened, and hard of hearing in 4 regions; services are delivered in 6 regions by Title VIIC-funded Independent Living Centers. • DHILS Programs serve 3 separate populations, each with unique needs: individuals who are Deaf and use American Sign Language (ASL), individuals who have acquired a hearing loss - i.e. those who become deaf suddenly or progressively and those who are hard of hearing. • Services include: skills training, peer mentoring and support, training in communication access to individuals and community agencies, training in self-advocacy, information and referral, and emergency intervention.

INDEPENDENT LIVING SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Rehabilitation Commission (MRC): Independent Living Centers				
Direct (consumer calls the IL Center)	• Significant disability which substantially limits an individuals ability to function independently in the community.	• Federal • State	Insufficient funding that results in 400-600 people with disabilities waiting for services statewide.	
MRC Turning 22[37]				
Indirect (local school district forwards the case to the appropriate human service agency)	• Individual must receive special education services and either graduate or turn 22. • Person must have need for continuing services. • Person must be unable to work 20+ hours/week in competitive employment.	State	• Referrals may not be timely which results in weak transition plans and/or a lack of adequate resources to cover an individual's needs. • Wait lists. • Services are subject to state appropriations.	

[37] Turning 22 (Chapter 688) is a transition program for students with severe disabilities between the education and the adult human service system. The process is area based so that an individual can stay in her/his own community. Two years prior to graduation from high school, or before turning 22 years of age, the local school district forwards a student's case to the appropriate human service agency that is then responsible for developing an Individual Transition Plan (ITP).

INDEPENDENT LIVING SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MRC Supportive Living				
Direct	• State resident • Must be at least 18 years old • Severe physical disability with mobility and/or cognitive limitations • Ineligible for services from DMH or DMR • Require PCA assistance and a case manager to live in the community.	• State • Federal	• Limited services • Waiting lists. • Inadequate funding.	
MRC Housing Registry				
Direct (Individual calls their local Independent Living Center)	• Open to anyone seeking information about accessible, affordable, public housing. • Public housing units require income eligibility.	State		Database for the Registry is managed by a non-profit agency; information on units in an area is accessed through a local ILC.

INDEPENDENT LIVING SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MRC Statewide Head Injury Program (SHIP)				
Direct	• State resident of any age. • Externally caused traumatic brain injury that results in significant cognitive, behavioral or physical impairment.	State	• SHIP has limited funding (state funded) and many consumers. Some wait lists for services such as supervised housing and ancillary support services • Limited number of providers with expertise in head injury • No coma management services available	• Head injury centers (6 in the state) do functional assessments • Centers work on site as well as in homes to facilitate community integration • Employment services done collaboratively with MRC • SHIP plans to implement a Medicaid Home and Community Based Waiver program in June 2002. The program will cover a range of

INDEPENDENT LIVING SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MRC Statewide Head Injury Program (SHIP) (continued)				
				community-based services including day programs, substance abuse, transportation, supported employment, family education, etc.

INFORMATION AND REFERRAL (I & R): ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR)				
• Direct • Indirect	Diagnosis of mental retardation or developmental disability	State		DMR area offices provide this service as part of intake and eligibility. Service coordinators use other resources for up to date information on services and supports.
Department of Mental Health (DMH)				
• Direct • Indirect	Anyone can call for general information services (eligibility determination to receive services is done at local site office).	State		• I & R services exist in both the central office (Office of Consumer and Ex patient Relations) and through local site offices. • Information regarding emergency services is available through local site office 24 hrs. /day.
Department of Public Health (DPH)				
• Direct • Indirect	Varies depending on program	• Federal • State	I&R services are limited to certain programs.	I & R services are a major component for programs in various realms such as some AIDS programs.

INFORMATION AND REFERRAL (I & R): ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Commission for the Blind (MCB)				
• Direct • Indirect - referred through registry for blind persons.	Identified as legally blind	Federal State		Services are provided directly by MCB employees - i.e. rehab teachers, social workers, counselors, etc.
MA Commission for the Deaf and Hard of Hearing (MCDHH)				
• Direct • Indirect	• Deaf or Hard-of-Hearing consumers, family members and others. • No age limit.	State	• Agency has a wide mandate and limited funding. • Information services are understaffed due to funding constraints, thus inhibiting aggressive development and dissemination of printed materials to assist hard of hearing people.	• Provides specialized information and referral for deaf and hard of hearing consumers, parents, and state agency personnel. • Provides specialized informational services for hard of hearing regarding communication needs.

INFORMATION AND REFERRAL (I & R): ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Office on Disability MOD)				
• Direct • Indirect	Service is provided through the Client Service Program, to any person with a disability, family or friend, throughout the state. No age limitation.	Federal (limited to VR clients) State	Funding limits available staff and the extent to which MOD can access information regarding services provided through non-profit agencies.	• Client Services Program receives 5,000 + calls annually. Many of those calls consist of more than one inquiry. • Client Services I & R is only one of its kind and primarily serves people who fall into cracks. • Program has 3 staff who are federally funded and 2 staff who are state funded. • It is the only program that provides cross disability information. A wide range of information is available. • It is not necessary to be an agency client in order to receive information. • Community Services Program provides I&R on ADA and other disability law related information. It also receives over 5,000 inquiries a year.
MA Rehabilitation Commission (MRC)				
Direct	Specific eligibility criteria vary by program.	• Federal • State		• I & R takes place at area offices which serve individuals based on geographical location. • Memos of understanding connect clients with services provided by other agencies.

INFORMATION AND REFERRAL (I & R): ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Division of Medical Assistance (DMA)				
• Direct: 1-800-customer service line • Indirect (Access to services is usually through physician referral.)	Must meet income and medical necessity eligibility criteria.	• Federal • State		• Information and referral on all aspects of Medicaid's MassHealth Program is available through its Customer Service "800" number. • I & R services are provided in many languages.
Department of Transitional Assistance (DTA)				
• Direct • Indirect	Program specific	State (services are delivered by state employees).	Limited to the extent that I&R service is provided through site offices rather than through a separate system.	• Recipient Services Program and Application Information Unit in the central office also provide I & R. A toll free number accesses them both. • If consumer is ineligible for benefits based on the information they have provided the Application Information Unit over the phone, they are informed that they still have the right to apply for benefits.

PERSONAL CARE ATTENDANT (PCA) SERVICES: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
Indirect (through Primary Clinician Care (PCC) program, a Medicaid Managed Health Care System).	Must meet Medicaid criteria for income and medically necessary.	Medicaid (Federal and State)	• DMH consumers who qualify for Medicaid and need PCA services receive health care services through their primary care physician (PCC). • PCA services are provided through a vendor agency. • Mental health and substance abuse services are provided through another entity, Mass Behavioral Health Partnership.	• DMH does not provide PCA services. Consumer obtains them through his/her health care insurer, including MassHealth. • MassHealth is the primary payer for PCA services as there are virtually no other insurance plans which cover this type of in-home support.
Department of Mental Retardation (DMR)				
Direct - referred by DMR area office if consumer is in a residential setting. If consumer is living at home, s/he must contact PCA vendor agency directly.	• Adults over age 22. • Consumer must meet criteria of **medical necessity**.	Medicaid (Federal and State)	• The eligibility determination process is layered between DMR and DMA. • Not as many consumer choices in PCA vendor agencies in some areas of the state. • Skills training is done sometimes before an evaluation has been conducted which determines level of need.	• Program operates through an ISA with DMA. • Individuals **receiving residential services** and supports through DMR and need PCA services or changes in those services are **reviewed,** and a recommendation is made, by a contracted **community agency**. • DMR does its own review and recommendation.

PERSONAL CARE ATTENDANT (PCA) SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Rehabilitation Commission (MRC)				
Program closed to new clients. Program at present serves 18 consumers working a minimum of 20 hours and requires PCA services due to physical disability.		State		• All referrals have been sent to CommonHealth since 1988. • See CommonHealth PCA Program (Division of Medical Assistance).
Ma Commission for the Blind (MCB)				
Direct - referred by physician who makes diagnosis of legal blindness.	• Registered as legally blind. • Must meet Medicaid eligibility criteria for functionally Impaired.	Medicaid (Federal and state)		• Consumer must be registered as legally blind and determined eligible for MassHealth. • MCB consumer is evaluated by a PCA vendor agency. Recommendation for service is then sent to MCB Medicaid Unit for review.
Division of Medical Assistance (DMA)				
Direct - services provided through vendors (e.g. ARCs, non profits, IL centers and Home Care Corps.)	Medicaid eligible and determination of "medically necessary".	State Federal		▪ Consumer is evaluated by a consultant (RN or OT who works for the vendor agency). ▪ Physician signs off on evaluation. ▪ DMA conducts clinical review.

TRANSPORTATION SERVICES: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Health (DMH)				
• Direct • Indirect	Must be client of DMH	State	• Not operated as a discreet service, therefore service varies within regions and among contractors. • Transportation in acute settings is very limited and relates only to medical services. Individual would not be provided transportation for recreational or social purposes.	• Most transportation services are contracted out to vendors providing service at local level. • Community based services such as clubhouses, provide transportation services for recreational and social activities. At times it may include pocket change for public transportation. • DMH budget has a line item for inpatient transportation services.

TRANSPORTATION SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Mental Retardation (DMR)				
Direct - i.e. referred from area offices	Must be a DMR consumer who receives services from residential or day programs, supported employment, or family supports	• State (majority of funds) • Medicaid • Federal (for those individuals receiving services on the Medicaid Home and Community Based Waiver).	• Funding • Waiting period due to insufficient resources • Individuals may not be able to access vehicles when needed. • Travel may be indirect and excessively lengthy in time and miles due to limited number of vehicles and many passengers sharing vans. • Lack of travel training and pedestrian skills for individuals who travel public transportation and are left off at bus stops. (Driver training is included in contract specifications with DMR vendors).	• Transportation services are provided for an estimated 8000 individuals. Budget is estimated to be about $25M. • Services are provided by RTAs in some regions through subsidies for public transportation, reimbursement to families for mileage, or programs in which vendors run the service through direct contracts with companies (this method is being phased out; as a result other general paratransit services are being impacted). • DMR, DPH and DMA coordinate transportation services through contracts with RTAs in some areas. • Safety monitors are provided only when appropriate (a medical or behavioral situation). • Consumer is transported door to door except on public transportation. **DMR provides a representative to work on transportation strategies through EOHHS' new office of Transportation Coordination.**

TRANSPORTATION SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
Department of Transitional Assistance (DTA)				
				No transportation is provided for services. In rare situations an individual who is in the Employment Services Program may be provided with a T pass or reimbursed for mileage associated with schooling or training of this program.
Division of Medical Assistance (DMA)				
Direct	Must be Medicaid recipient and meet that eligibility requirement before they may be provided with transportation services for a trip to the doctor or other medically related needs.	• Federal • State	• Consumers who receive services under coordinated/brokerage transportation plans such as the RTA, feel it is extremely inconvenient and time consuming. Previously they could directly arrange their transportation services destination but now with the brokerage system they have to go through various procedures. • Physicians may not fill in and mail the PT1 form that authorizes transportation services for patients' medical needs. As a result appointments may be missed.	• Transportation services, such as a T pass, paratransit, or mileage may be provided for a trip to the doctor or other medically related needs. • Physician must authorize the need for services for reimbursement. • Reimbursement is retrospective.

TRANSPORTATION SERVICES: ADULTS (continued)				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA Rehabilitation Commission (MRC)				
Direct - through local area office	Must be VR client	• Federal - State • Some client co-pays	Travel may be limited in rural areas.	MRC coordinates services where feasible with DMR.
MA Commission for the Blind (MCB)				
Direct	Must be VR consumer or in MCB social service program.	• Federal • State	Travel services are very limited	• MCB's mobility training program provides skills in accessing public transportation (where available) for blind consumers.

VOCATIONAL REHABILITATION SERVICES: ADULTS				
ACCESS	**ELIGIBILITY**	**FUNDING SOURCES**	**BARRIERS**	**COMMENTS**
MA COMMISSION FOR THE BLIND (MCB)				
▪ Direct ▪ Indirect Client contacts local VR office to apply for services	▪ Significant disability that impedes employment ▪ Reasonable expectation of an employment outcome	▪ State ▪ Federal	▪ Limited funding ▪ VR counselors' heavy case loads Interfere with working effectively with new industries ▪ VR counselors have limited experience of new disabilities (e.g. chemical sensitivities, chronic fatigue syndrome) ▪ Society's paternalistic attitudes toward people with disabilities conflicts with their obtaining employment opportunities.	▪ Clients work with VR counselor to develop Individual Plan for Employment (IPE) ▪ Some support services available to clients after employment is gained
MA REHABILITATION COMMISSION (MRC)				
▪ Direct ▪ Indirect Client contacts local VR office to apply for services	▪ Significant disability that impedes employment ▪ Reasonable expectation of an employment outcome	▪ State ▪ Federal	▪ Limited funding ▪ VR counselors' heavy case loads Interfere with working effectively with new industries ▪ VR counselors have limited experience of new disabilities (e.g. chemical sensitivities, chronic fatigue syndrome) ▪ Society's paternalistic attitudes toward people with disabilities conflicts with their obtaining employment opportunities.	▪ Clients work with VR counselor to develop Individual Plan for Employment (IPE) ▪ Some support services available to clients after employment is gained

APPENDIX D

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